



ARIZONA  
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CONSORTIUM

RESEARCH  
REGISTRY



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# Clinical Therapeutics Core and Alzheimer's Research Registry

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## The Arizona Alzheimer's Consortium

- A state-wide, non-profit organization dedicated to the scientific study, early detection, and prevention of Alzheimer's disease.
- Recognized as a productive model for scientific collaboration.

# Arizona Alzheimer's Consortium Members



**Banner Health**



**Sun Health**



**Arizona State  
University**



**TGen**



**Barrow Neurological  
Institute**



**University of  
Arizona**



**Mayo Clinic Arizona**



**Southern Arizona  
VAMC**



# Clinical Therapeutics Core Goals

- Increase awareness of clinical therapeutics research related to dementia and Alzheimer's
- Expedite enrollment in Alzheimer's related studies by creating a research Registry
- Enhance and expedite clinical therapeutics research within the Consortium
- Supported by The Arizona Department of Health Services

## Why was the Registry created?

- A major obstacle to finding new treatments and preventions is testing these methods for effectiveness
- Large numbers of study participants are needed in a short period of time to participate in AD-related clinical research studies: people with AD, mild cognitive impairment, as well as cognitively normal volunteers

## **Who can join the Registry?**

- **Anyone 50 years old or older**
- **English-speaking**
- **People with Alzheimer's or other dementias**
- **People with possible Mild Cognitive Impairment**
- **People without memory impairment**

## Research Options\*

For people with a diagnosis of AD or MCI

- Clinical trials of medications (5)
- Vaccine studies (4)
- Genotyping/Biomarkers (3)
- Diagnostic tools (1)
- Longitudinal (1)

\* Currently available in the Consortium; most studies include imaging



## Initial 1<sup>st</sup> Year Goals

- **Build infrastructure**
- **Enroll 20 participants**

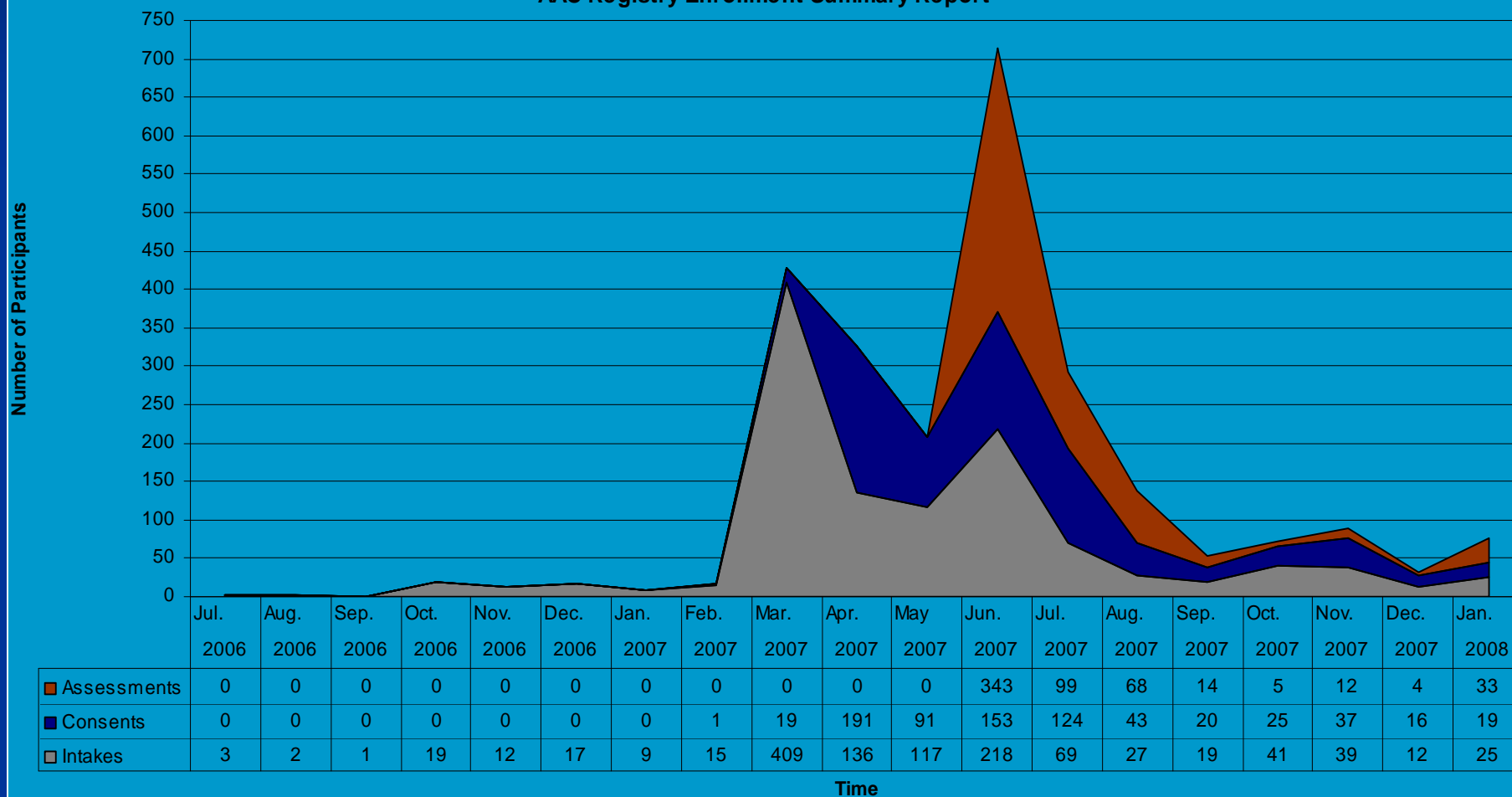


## Marketing and Outreach

- Launch March 22, 2007, with prominent media coverage
- Free Memory Screening Events
- Registry Information Seminars
- MCI Information Events
- Direct Mail Postcards
- Website
- Newsletter

# Intakes

**AAC Registry Enrollment Summary Report**





# Database Tracking

## RESEARCH REGISTRY

<b>AID</b>	<b>Name</b> Mrs. Myra Testpatient	Mrs. Myra Testpatient	Mrs. Kayla Testpatient	daughter	diag
<b>A</b>	ggdsd	1694 W. Glendale Ave. #443 Avondale, AZ 85252 8980 (602) 589-8149	1234 Nogales Lane Phoenix, AZ 85011 (602) 555-5521	<b>Find Registrant</b>	
<b>51397</b>	Possible MCI			<b>Reports</b>	

Tracking Info	Participant Info	Contact Log	Questionnaire	Telephone Assess	Diagnosis Hx	Referral Summary
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<b>Print Intake</b>	<b>Intake Complete</b>	<b>Sent/Complete</b>	<b>Rec'ed Items</b>	<b>Outcomes</b>	<b>Events</b>
<b>Email Packet</b>	<b>Welcome Packet Sent (Q)</b>	7/10/2006		Normal	<b>MCI Invitee</b> <input type="checkbox"/> <b>MCI Letter</b>
<b>Small Packet</b>	<b>Survey Received</b>	1/6/2008			<b>MCI Invite Date</b>
<b>Survey</b>	<b>Consent Sent &amp; Received</b>				<b>MCI letter Date</b>
<b>Send Consent</b>	<b>Consent 2 Received</b>		1/6/2008		<b>Newsletter Date</b> 11/7/2007
<b>HIPAA</b>	<b>HIPAA Sent</b>	10/12/2007	1/10/2008		<b>Research Conference</b>
<b>Assent</b>	<b>Assent Sent</b>	10/12/2007			<b>Invite 10/31</b>
<b>F/U Letter</b>	<b>F/U Call Complete</b>				<b>Cognitive Assessment Scheduled</b>
	<b>No Contact Letter</b>	9/18/2007			<b>CA Schedule Date</b>
	<b>Registry Label Created</b>	8/9/2007			<b>Screen Time</b>
<b>Questionnaire</b>	<b>Q D/E and Rec'ed</b>				<b>Screener</b>
<b>CReview</b>	<b>Consent Review Form</b>				
<b>Audit</b>	<b>Chart Audit Print</b>				
	<b>Delay Letter</b>				
	<b>Consent Reviewed w/ part.</b>	2/7/2008			
<b>Cog. Testing</b>	<b>Cognitive Assessment</b>	2/7/2008			
<b>DX Letter</b>	<b>DX Letter Sent</b>	12/5/2007	2/8/2008		
<b>MS Sun Fax</b>	<b>Sun Referral Fax</b>	12/12/2007			
	<b>P.I. Referral Triage</b>	1/1/2000			
	<b>Referral Triage Part. Call</b>				
<b>OUT Referral Fax</b>	<b>Site Referral Sent</b>				
<b>Pscrn Letter</b>	<b>Prescreen Reminder</b>	10/12/2007			
<b>Prescreen</b>	<b>Prescreen Visit</b>	1/1/2000			
	<b>Incoming Referral Outcome</b>				
	<b>Part. Post Referral Call</b>				

<b>Participant</b>	<b>Initialed</b>	<b>Witness</b>	<b>POA</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The participant did not verbalize any

2/7/2008 Possible MCI

No No

☐ Tariot ☐ Sabbagh

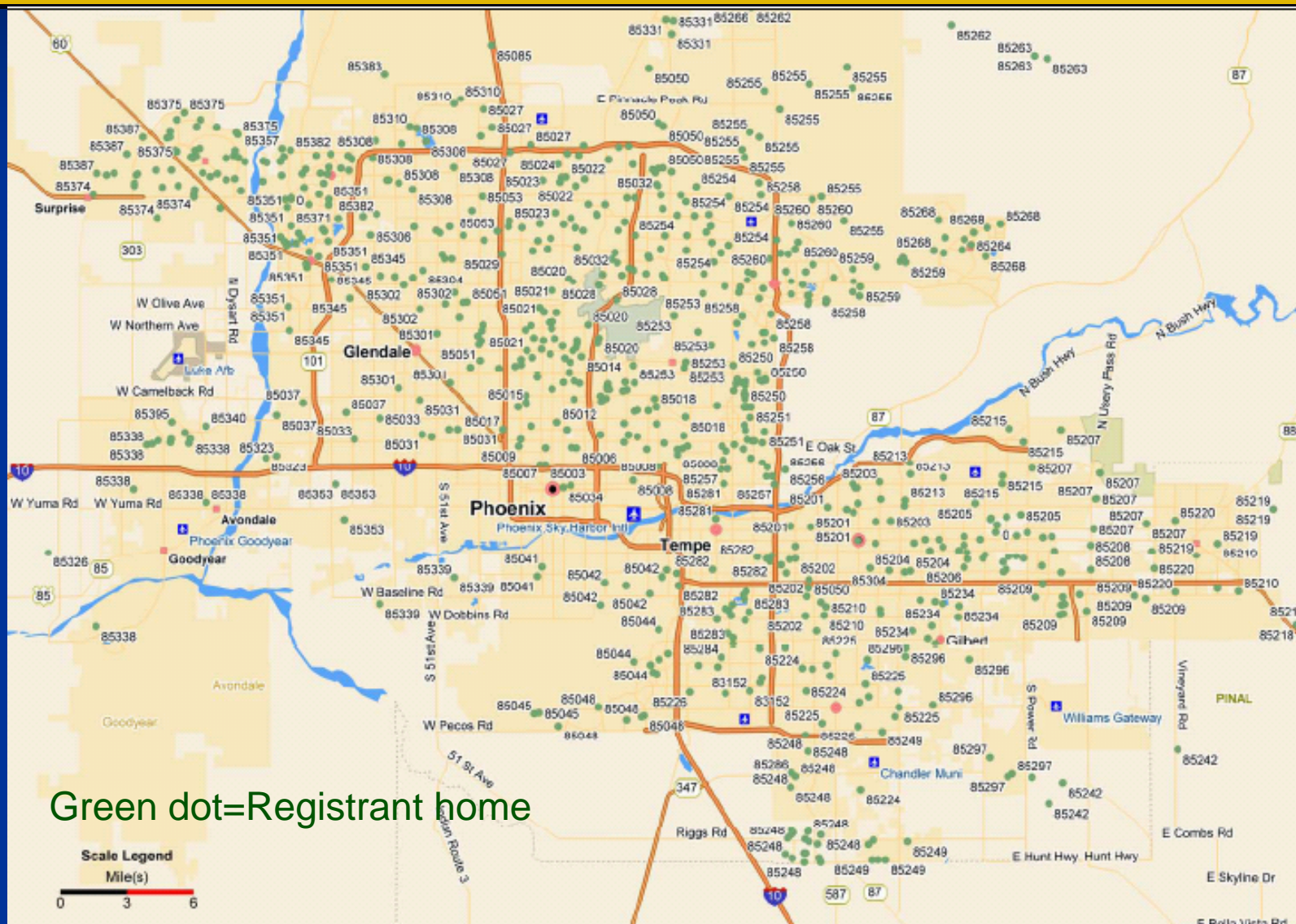
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## Enrollment Summary April, 2008

- 1245 Intakes
- 783 Enrolled
- 640 Tested
- 63% Enrollment rate
- >5000 follow up phone calls

# Registrants By Zip code





## Welcome Packet

- Welcome Letter
- Questionnaire
- Brochure
- Consent Form
- HIPAA Letter
- HIPAA Authorization Form
- Banner Notice Of Privacy Practices



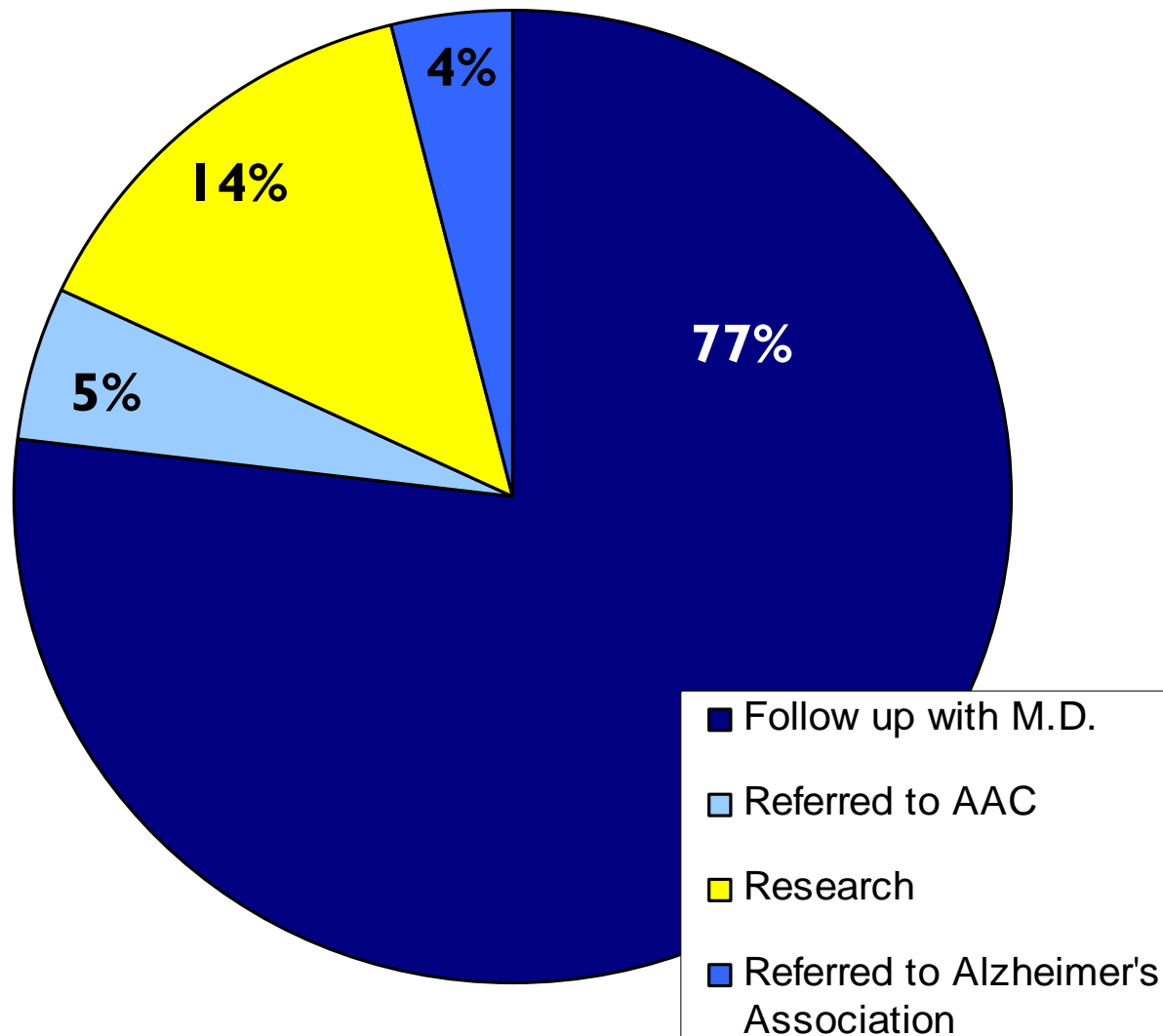
## Memory Assessment Instruments

- Functional Memory Screen
- Telephone Cognitive Interview Screen
- Verbal Learning Test





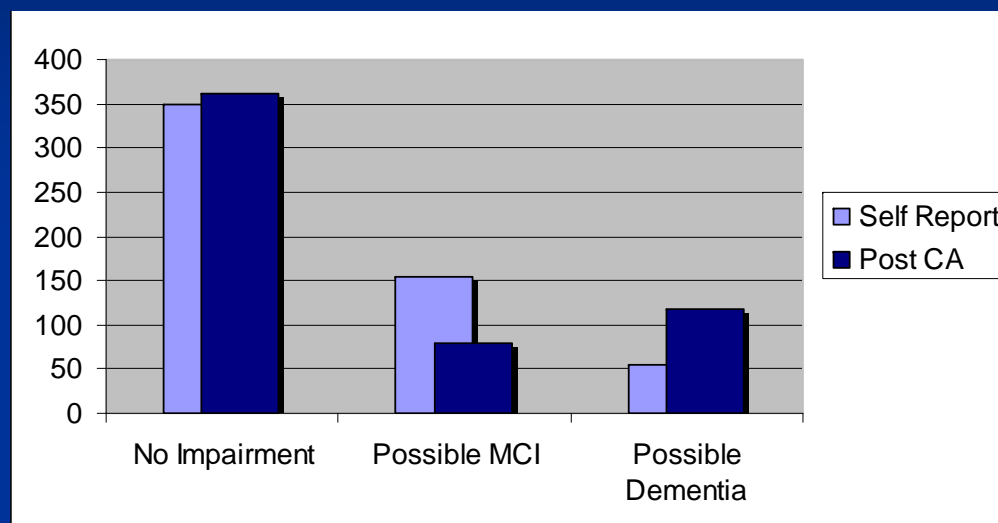
## Participant Outcomes





# Assessment Results

40% who had objective



Cognitive Status	Self-Report	Telephone	Percent
No Impairment	350	361	+2.0%
Mild Impairment	154	80	-13.3%
Significant Memory Impairment	54	117	+11.3%

# Study Interests

Study Type Interest	Subjective Memory Impairment	
	Mild/Significant Memory Loss	Normal
Brain Imaging	57%	67%
Disease Slowing Treatment	56%	56%
Non-treatment	52%	75%
Prevention	52%	60%
Lifestyle Intervention	48%	66%
Vaccine	44%	42%
Genetic	39%	55%
Brain Donation	30%	37%

## *Other Progress: Forging New Alliances*

### **Arizona Alzheimer's Consortium Site Evaluations**

- Site evaluation tool developed
- All 6 site visits completed
- Site resources (staff and facilities) catalogued
- Site studies catalogued and stored in CTC database
- Site visits included discussions on research collaboration, training and interactions with the Registry
- New multicenter trials brought to Consortium sites

## Progress:

### Exploring a Consortium-wide Common IRB

- Approximately 50 people attended a statewide meeting summer 2007
- All institutions represented by leadership, legal, clinical investigators
- Co-sponsored by Arizona Biomedical Research Council
- Facilitated by Kristen Rosati, Esq.
- Hosted by the Flinn Foundation
- Momentum continues

- The Registry represents a novel approach to clinical recruitment for research related to Alzheimer's disease.
- This model was well received by the community, which was thirsty for information about the course, diagnosis, potential treatments and resources available for AD.

- For many people, participating in the Registry represented a first step for investigating their own memory.
- The tools developed for the project including the memory assessment battery and the Registry database have proven to be effective for prescreening for studies and have facilitated enrollment for Consortium members.
- The model may be replicated elsewhere.



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## Alzheimer's Research Registry

February 2008

